How To Find Reliable Cancer Info Online Transcript

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Introduction and Guest Welcome

Welcome again, everyone, to this episode of the Prostate Cancer Summit today. I have a special guest Darrel. Mitteldorf, So Darryl founded, male care and other amazing support groups for prostate cancer.

And that's what we'll talk about and other things. Darrel, first of all, thanks for being on. We we chatted for a while prior to recording just catching up.

You're here in New York and, you know, is like your next door neighbor. You really never get to see your next door neighbor that often, and it feels the same way with you.

We're in the same city, but we never get to see each other. So very nice to have you on. Thank you. Geo. It's it's amazing that, we don't physically see each other except perhaps on conferences.

But we see each other on zoom once in a while, and not even very frequently on that, but, totally happy, to be recording with you today. Thanks for inviting me.

My pleasure. I thought of you immediately when, when Brett and I. So Brett runs Doctor Talks. He's been doing this summits for 15 years on different topics.

This is the first prostate cancer summit. Going to be a huge hit for those that are watching. And I think we got to have Daryl on, from Mel Care. So Daryl, tell us tell me a little bit.

I mean, I remember I must when I first came to NYU 15 years ago, I probably met you then and I gave a talk to one of your support groups. Then how old is male care?

Tell us a little bit of how you. Why? I mean, I don't think you. I don't remember having a conversation or think that you've had prostate cancer. Why prostate cancer focus and all your other organizations and just kind of take this in whatever direction you want for now.

Sure. And we'll try and do this in 90s or less, because why would anyone care about our history? But, I'm glad to share it. So like in the early to mid 1990s, I was social worker, but I was also working as a refugee resettlement officer and a variety of conflict zones in Europe and, sub-Saharan Africa.

learned that my dad was diagnosed with prostate cancer in 1998, came back to the United States, came back to New York, where my family lives. And, lo and behold, he had prostate cancer.

How Malecare Began

And lo and behold, he was going to die five minutes later, as I was expecting, based on just my imagination and ignorance about cancer in general and prostate cancer specifically.

It's the C-word, right? The cancer is cancer in your head. At that time, it didn't matter if it was prostate or lung cancer at the time, maybe. But what you and you know, it resonates and, relatives and friends almost as much as it does in the patient, no matter how far.

I mean, I'm 6000 miles away from my dad. And yet I'm shaking in my gut and upper chest, probably just like he was. It wasn't until I learned more that I was able to calm down, and I wanted to help him learn more.

So I started having no career at that point since I basically blew it all, you know, basically left without permission more or less from my tasks. And I happened to be in Kenya at that moment, and needed there.

But my dad needed me more. I started a support group locally at a local hospital that's now out of business called Beth Israel. It's now part of Mount Sinai.

But, started a support group for that. Him, based it on a model from the US two organization. Very quickly realized that model sort of wasn't really helping people.

It certainly wasn't helping my dad. But what I learned from work, from creating the support group, was that many men presenting with prostate cancer, older men, facing their mortality and adjustment, both to their careers.

If they had, you know, financial problems, emotional problems and treatment choices that even the late 90s, 1990s were available to them. It was very similar to what refugee people were experiencing when they were, you know, had their villages, towns or cities under fire and had to, you know, pack up at the last minute and move themselves and perhaps family members to a new location with basically the sandals on their feet, you know, clothes on their back and whatever money they can gather quickly.

The phrasing is around adjustment disorder. How do you adjust to a dramatic and, and, and devastating new situation in your life that's bound to be chronic, meaning you're not going to die immediately as a consequence of whatever the problem is.

So using what I learned with refugees, I developed a set of modalities, in the realm of psychosocial psychology, social, for men with prostate cancer.

And that became the model that was used for the first male care groups. And that model actually spread really fast, like certainly by the year 2000, there were a lot of hospitals throughout the United States, a lot of social workers and psychologists learning from me, you know, writing the emails at that time, or we talking on IQ, which was a way to communicate at that time.

You know, just figuring out this is really good. The other models used by the American Cancer Society, the society thing, cancer care, they all blew and didn't really help people.

What? So I was very proud of that. But also, it was really good to be able to help a lot of guys and mass and scale and realized this is my second calling, you know, living and caretaking for my dad, who lived another seven years.

And, you know, helping men that I've never met with their cancer from those groups. And being in New York, I was also exposed to underserved communities that were analogous to those that I was meeting in Europe.

People from Africa now transposed to living in Finland or Spain. How do they integrate into society? How does a cancer patient integrate in a society?

How does a black Latino cancer patient faced barriers that were still prevalent and the late 90s and really still prevalent in many places to this day?

People in the South dealing with residents of Jim Crow laws and such, people from LGBT community facing barriers around being able to talk to their doctors about their unique concerns, such as imagine being an angel and sort of, man, who's now faced with impotence and faced with the opportunity to do an origin declaration therapy, which from a gay perspective, is a form of punishment that's offered to people who are caught, so to speak, as being homosexual.

Those kind of issues were novel at that time. And we discussed them. We promoted them. We exposed the problems and barriers that these guys and their families and friends were facing and developed ways to overcome those barriers.

And that became male care. You know, around the structure of the organization, you know, we built, parallel nonprofits, the world's first LGBT focused cancer patient advocacy organization, the National LGBT Cancer Project.

Not the world's first black men's cancer organization, but I think one of the more enduring ones, the Black Prostate Cancer Alliance, and then lots of other interventions using technology as it emerged through the years 2000 till this very moment, using generative AI and such, we're known for being innovative, which is really cool.

But I like, you know, and people have described us and I love this, that we're like the Apple computer, a single oncology.

Diverse Support Groups and Peer Connection

But in fact, we're now what we really do is listen to the patients that show up to our support groups, both in person and online, and we respond to them with ways that help address the problems that they're facing.

And by listening, we've learned problems that nobody would have imagined. Not pharmaceutical companies that hospitals, not major doctors, not minor doctors.

You know, it's only within the context of people talking to each other, peer to peer sharing their concerns. Cancer patient, cancer patient and myself and my colleagues sort of eavesdropping, if you will, but innocently and anonymously to, you know, to sort of understand what's going on and then figure out ways to fix it.

So that's meal care in a nutshell. Beautiful. And it sounds like, very unique in many ways, certainly in, representing the underrepresented. Right. So you talked about the LGBT community, Latinos and blacks.

I remember the time where I gave a talk to your group. It was the most diverse support group I've ever seen in terms of, in terms of race and sexuality and, and all sorts of things.

It was, you know, even perhaps even demographically, you know, even wealth. You know, there were people that I think, after having conversations with them were entrepreneurs and wealthier than others.

Others were blue collar. And it was just beautiful. Just, you know, everybody's there, you know, for the same reasons. You know, it. And maybe it's analogous, maybe it's not, but I, I've sent people, several patients of my to, you know, Alcoholics Anonymous.

I think that's one of the most extraordinary organizations that exist. And one of the beauties I've gone to some meetings, just out of curiosity, is, wow, everyone is here.

I mean, literally a homeless person at these meetings and, you know, a CEO of a bank all here. And sometimes they were, actresses and actors that are there that, you know, that.

And they were all there for this one reason. And we're all the same in this in this particular situation, we're all the same. It sounds like male care is very much like that.

Totally. I mean, so the idea that, many of our counterpart organizations have support groups that basically look homogeneous or homogenous or they look the it's just the same folks and ours are really diverse, both economically.

You know, we have captains of industry, as you noticed, and homeless people sitting side by side. It illustrates the impact of disease. Disease doesn't care.

You know, that ultimately we are traveling inside of humanoid bodies, and those bodies react to environment. They react to genetic. They they carry the genetic legacy of wherever their families or whatever came from.

And ultimately, we share disease profiles that are totally agnostic to what we do, where we come from. You know, to some extent where we come from to some extent, you know, what opportunities we've had in life and what the common spine that we all share, ours, our emotional content, our emotional lives.

Fear is genuinely homogenous. If you will. You know, anxiety affects all of us in similar ways. Our emotional lives are not determined by almost anything beyond what the disease is doing to us in our heads.

And that's where peer to peer support plays out so beautifully in that you have people sharing insight and knowing, hey, they're not alone. B they're still alive, is they could see a reflection of themselves in the person opposite them and in front of them, and, you know, they they could come up with strategies develop in neural networks that other places can't develop.

That's beautiful. So how where can people find, male care support, group to join anywhere in the country or the world? How does that work? So I it is good that you mentioned the world because our model is replicated globally from Iceland to South Africa and Australia, through most of Europe, etc..

You could start at male care.org and male care is spelled m a l e not a male, you know, care. You know, and you know, just, follow through from, you know, clicking through on different things until you find something.

Most of our work now is done online. I mean, our online support groups are massive, and in a way they're most helpful compared to the in-person. The in persons have, groups which still exist and, you know, have, you know, you know, risen like the phoenix and covet, they almost serve a different purpose, more of a social purpose and more of a patient navigation focus, people hand-holding each other to appointments or driving them home after a procedure, etc., or hanging out with their families and such.

But the online groups are 24, seven, there. Yeah. I mean, the, the, the they're passed out in different stages. So there are advanced groups for metastatic people, advanced groups for people who are just doing radio like, and therapies, etc..

And there are newly diagnosed groups. There are people for complementary medicine people, folks that diet caregiver groups, etc.. You know, I mean, just on and on and on with the idea and groups for just gay men, you know, people just interested in a particular impact on lifestyle, etc..

And I'll tell you, the largest groups that we have with over 50,000 people online is anxiety support, right? You know, because that affects everyone. Yeah.

What's different between I mean, bias aside, what's different between male care and let's just say other support groups. There's 3 or 4 others, US two Prostate Cancer Foundation, there's a few others.

What's different. Yeah. And it's not I mean, I think we have to own up to our bias because as clinicians and, and I'm a, an oncology social worker, you're a clinician.

We want to understand what's the optimal procedure or patient or therapy or opportunity for treatment or a way to help.

How Malecare Groups Work

The best way to help our patients live longer and happier lives. So it's not even about bias. It's about our assessment of what's good and bad, or at least better.

And what makes a male care group better is, a number of things. One is that it meets frequently. I mean, it's not like a one shot a month kind of thing.

It, it's they meet every at minimum every week. No matter what location. And of course, the online groups are always on the opportunity to meet other people, no matter what their background is.

As you, you know, well pointed out, is there that doesn't exist among the other organizations, at least to the extent that it does in our thing and that our groups are about caring.

We're constantly evolving how we do what we do. I mean, we've iterated our main modality of of of hybrid psychosocial and didactic intervention, probably 80 times by now since we started in like, you know, the late 1999, I guess, or so.

See, other groups are still doing the same model they did 100 years ago. You know, I mean, it's it's not, you know, we we're a bit almost like the education system we were talking about with regards to our sons at the public.

School systems are still teaching like they taught 100 years ago, and they haven't, evolved much. Yeah. I mean, our group leaders are interested in doing the best they can do.

You know, we have one word scene that sort of underlies everything that we do. And that word is better. Everything has to. We have to, which means we have to know where we're at.

Right now. So we could do something better in the next moment. And that requires a lot of care, a lot of thinking, a lot of smartness, and a lot of time and commitment.

Our group leaders, for the most part, are psychologists or social workers. They're trained, they understand what's going on, and almost all of them have skin in the game, meaning they're diagnosis for prostate cancer.

They also know not to advocate just for the choices they've made. In fact, they're told not to even talk about the choices that they've made. That's very interesting point.

That's right there for one second. Sure. Lots of these support groups. And so I've seen a lot of that. That may be one of the key differentiators between perhaps your organization, male care and the others.

Many of the others I see that, one gets up one and, you know, talks about their prostatectomy and then the other guy comes and you tell me about your prostatectomy.

And he's like, well, you have to take you got to take it out. What are you thinking? Just take it out. And as we know this, this is not a one size fits all.

It is different. And now, relative to when we first met, there are, I don't know, a dozen treatments for prostate cancer, if not more, not to mention lifestyle methods that seem to work very well for, particularly those on active surveillance.

So, it's so that was a turnoff for me in many other places. So in male care, is it, rule for incomers and, and members to not talk about their particular treatment that they underwent and kind of encourage others to do the same?

How does that work? I mean, no one's I mean, we don't I mean, outside of just basic no being a jerk, but I mean, we don't have rules, right? But, but no people can talk about their their what's going on for them.

I mean, that's 90% of what they're there for, and everyone else listens. But the moderators, the group leaders, are trained and we train our I mean, you know, they're not going to boot camp for six weeks, and, you know, but, I mean, they're they're getting trained and they're getting trained, and, by month, by annual, follow ups, to make sure people don't sort of push their therapies on other people.

Everyone is there to respect everyone else. Everyone understand? I mean, if there's one rule, what we understand is, you know, nobody knows anything. You know, I mean, until there's a valid a validated, side effect free way to permanently reduce death from prostate cancer.

So you'll live to 120 and die in a bus accident. Everything is on the table outside of the obvious things like leeches or, you know, you know, whatever, you know.

Yeah, mud or however that plays out. So the idea. But but see, no, I mean, people respect and communal

understanding that your part when you enter a male care group, you're joining a neural network.

It's not just your brain, it's 102,000. Other brains that are being are sharing information because it's not just the group. The group leaders know what's going on to a large extent, remarkably, in all the other group situations, both online and in person.

So when a trendy topic comes up or concerns that nobody has discovered, you know, emerges, let's say in, Wichita, Kansas, in our group there that is discussed nationwide in all of our groups at some point and seem to basically to test out, is this a universal problem that nobody's found in a clinical trial?

Or, and, and in real world, experience? But bottom line is, no one is forcing anything on anybody. If you want to sit around with active surveillance with the Gleason ten and distant metastases, people will probably discourage you a bit.

And plus, you know, and and ask you questions about, you know, what that's like for you knowing, you know, out of curiosity more than. Yeah, encouraging a certain, treatment approach.

Right. And out of care and love. I mean, there is a sense of love that's generated within these groups. That's not at all wacky or fringy or difficult to deal with.

I mean, people I mean, you, the emotional content in each group is the gold that people take home with them. They feel like they've connected with strangers in a way that they're not going to ever connect.

That the local, Red lobster or baseball game or, you know, what, have you or chance meetings at a gas station. These are groups that are special.

Cancer Academy and Patient Education

They're about people that when they entered the room, one of the predicates is your life may end sooner than later, you know? And we hope that's not true.

But everyone's thinking that, you know you, that your life will be a bit more miserable than you might have imagined before the day you were diagnosed.

But at the same time, you're in a room of people that are thriving, that are happy, and somehow they found a way to achieve that sort of feeling of goodness in their lives and value in living longer and making good choices around their lives.

And they want to share that with you, but not impose it on you. That's lovely. Tell us about cancer Academy. What is it and how does it help? So as I said earlier, one of the things that makes people anxious is not knowing stuff.

And how does any patient in any cancer diagnosis learn about anything? Usually it's the 15 minute consult with their doctor if they're lucky, and the first time around they'll get an hour, but then it'll be much briefer.

Maybe you'll have a nurse practitioner that's really cool. That can explain things. Maybe you'll go online and read stuff. But long story short, there's the way we teach people about disease sucks, particularly around people who are newly diagnosed, who are in no frame of mind to sort of take a test or understand or read a PDF or watch a webinar, or listen to their doctor after they hear the word cancer, which is, you know, which is like, Charlie Brown episode after you hear the word cancer, where the the you cannot even hear the words correctly after that.

Yeah. Fireside Theater actually. So yeah, yeah. I mean, it's like the well, the deal is like, your dog, doesn't understand English, except he knows food or or the right time to eat or get.

Let's go out. You know, he'll just understand the sounds that are affiliated with an activity. It's the same thing with the word cancer. Unfortunately, the activity is death.

The activity is misery. The activity is confusion. Anxiety. I don't know what the hell is going on. So long story short, we created this thing called Cancer Academy, which is a new, one of a kind way to teach cancer patients about their disease in ways that are digestible, easy to understand.

We have, so you go to Cancer academy.org. And you'll see a list of these many courses, these 3 to 5 minute, you know, opportunities to learn about very discrete issues related to your therapy or whatever.

So the goal is twofold, one, to level the playing field between you and your doctor. When you sit in that doctor's office next time around, you're going to feel like you know what you're talking about.

And you know what the doctor's talking about. Second thing is to reduce the anxiety that you have 24 seven, even if you're not aware of it, to make it even less, you know, a wearable, you know, that, consciousness for you.

So by learning about your cancer through these little courses that are free, that are available online, you know that 24 over seven, you don't have to, you know, sign up for anything or you put your email address in there, but that's about it.

You know, I mean, you're a we may invite you to, you know, do a survey, but that's here or there and you get an alert, that kind of thing. Basically, these courses are for you.

If you could imagine web MD and Coursera or edX having a love child, that would be Cancer Academy. But mostly that love child is your child and it's for you and you're not raising it.

That child is raising you, raising you to a feeling of calmness and authority and competence around your cancer. And the other advantage, because we are a multicultural organization, so to speak, and we are focused on underserved communities, it reduces what's called, health inequities.

Meaning like the idea is that doctors are less likely to explain things to black people than to white patients, to white people. Our doctors are generally presenting as heterosexuals, so they won't know how to speak to an LGBT person or doctors that are unaware of the challenges that being in a rural community may pose for people seeking treatment in a suburban, urban kind of center.

You know, so the upper and also their courses for children, you know, like how to talk to dad or mom about their cancer. Right now, Cancer Academy is almost entirely focused for prostate cancer patients.

But over this coming year, and by the end of 2025, we hope to have 195 cancers covered in content. Beautiful site. Yeah. Beautiful resource, important resource.

I think for patients, I think you're absolutely right. I, I although I wasn't trained as a social worker, I've always been very curious. The mind body connection, psychology, why people do what they do, what gets people excited, what gets what, what induces fear.

So I always pay very close attention to the words that they use to describe their situation. Particularly in prostate cancer. So I think this could be a game changer, honestly.

And, and, and just help people with just more clarity, as you said, to calm, calm the nervous system a little bit more. I hope you're not too good because people actually pay me part of the part of the reason why I have a concept that people are willing to pay out of pocket.

One is to put them on interesting natural protocols, but the other is to help them navigate. So this is what I have. What should I do? So first thing first, let's take five deep breaths and calm down the nervous system so we can make the best decision possible.

And here are your options eight. Here are your options here. These are not your just give them that kind of clarity, which it sounds like, Cantor Academy will be doing that for for patients or some element of that.

So Cancer Academy is also helping you in your practice and that it's, it's taking a load off of the basic information conveyance that you'll be doing and being able to personalize your conversation with your patient as well as the patient, personalizing their needs and expressing them to you.

So yeah, you'll do that, you know, take five breaths, but you'll be able to do five more breaths because you didn't spend time teaching a patient about, you know, the benefits of lycopene or, you know, tomato eating or whatever, you know, because they've already gotten that.

In fact, you may prescribe, let's go to Cancer Academy and take course number 12, number 18, number 32, before you come to me, before you visit. Beautiful, beautiful. I love it, Daryl.

Thank you so much for being on. This is, you know, I think this gave the audience and even myself a just a general perspective of what happens in these support meetings, which I think a lot of people are confused about.

And what's the, you know, what's different between one and another and any other and particularly male care. So I appreciate your time. Any final words and where can people contact you or male care.

Closing Remarks

No, I mean the web is the way to go, really. You know, it's, it's still is, canceracademy.org, malecare.org. You could go to lgbtcancer.org if that's your thing, you could go to Black Prostate Cancer alliance.org if that's your thing.

Or if it's not your thing, you'd be just fill your curiosity up and, go learn about how your brothers and sisters are living their lives. But most and that on.

ChatGPT a number of the GPT that are cancer related were all developed by male care. We have a strong relationship with open AI and Microsoft. You know, and that's a beautiful thing of, living in, you know, third or fourth quarter of 20, 24 and moving into 2025.

You know, we have the opportunity to do things online and with coding and they AI and things that we have yet to imagine all to help ourselves, our brothers and sisters, our friends that we have yet to meet.

And we love that. And, we love you for, you know, taking your time today to learn more about this. Thank you so much, Darryl. Thank you again. Everyone, thank you for watching this episode of the, Prostate Cancer Summit with Darryl Mitteldorf.

I hope you found it useful. I know you did. I'll see you next time at the next episode. So long and take good care of yourself.